Family and health professional experience with a nurse-led family support intervention in ICU: A qualitative evaluation study

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Abstract: OBJECTIVES: To investigate family and health professional experience with a nurse-led family support intervention in intensive care. DESIGN: Qualitative evaluation study. SETTING: A twelve-bed surgical intensive care unit in a 900-bed University Hospital in Switzerland. MAIN OUTCOME MEASURES: Data were collected through 16 semi-structured interviews with families (n = 19 family members) and three focus group interviews with critical care staff (n = 19) and analysed using content analysis strategies. FINDINGS: Four themes related to the new family support intervention were identified. First, families and staff described it as a valuable and essential part of ICU care. Second, it facilitated staff-family interaction and communication. Third, from staff perspective, it promoted the quality of family care. Fourth, staff believed that the family support intervention enabled them to better care for families through increased capacity for developing and sustaining relationships with families. CONCLUSIONS: An advanced practice family nursing role coupled with a family support pathway is an acceptable, appreciated and beneficial model of care delivery in the inttensive care unit from the perspective of families and critical care staff. Further research is needed to investigate the intervention's effectiveness in the intensive care unit.

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Research Article

Family and health professional experience with a nurse-led family support intervention in ICU: A qualitative evaluation study

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ABSTRACT

Objectives: To investigate family and health professional experience with a nurse-led family support intervention in intensive care.
Design: Qualitative evaluation study.
Setting: A twelve-bed surgical intensive care unit in a 900-bed University Hospital in Switzerland.
Main outcome measures: Data were collected through 16 semi-structured interviews with families (n = 19 family members) and three focus group interviews with critical care staff (n = 19) and analysed using content analysis strategies.
Findings: Four themes related to the new family support intervention were identified. First, families and staff described it as a valuable and essential part of ICU care. Second, it facilitated staff-family interaction and communication. Third, from staff perspective, it promoted the quality of family care. Fourth, staff believed that the family support intervention enabled them to better care for families through increased capacity for developing and sustaining relationships with families.
Conclusions: An advanced practice family nursing role coupled with a family support pathway is an acceptable, appreciated and beneficial model of care delivery in the inttensive care unit from the perspective of families and critical care staff. Further research is needed to investigate the intervention's effectiveness in the intensive care unit.

Implications for clinical practice

- Specific models of family care are necessary to meet family support needs and to better enable ICU nurses and physicians to care for families of critically ill persons.
- We found that nurse-led family support, consisting of proactive, relational engagement of families over time, facilitation of communication and interaction between families and critical care staff and psychoeducational and relationship-focused family nursing interventions is a useful, feasible and acceptable model of care delivery to families.
- The study suggests an advanced practice family nursing role, drawing on a relational family systems approach has the potential to improve the quality and efficacy of care provided to families of critically ill persons, and to increase ICU teams' capacity and ability to meet families' needs.

Introduction

Critical illness with admission to an intensive care unit (ICU) is an overwhelming and stressful experience for patients and family members alike (Alfheim et al., 2018; Eggenberger and Nelms, 2007; Wiegand, 2012). Families experience profound uncertainty and distress during the patients' critical illness (Minton et al.,

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2019; Turner-Cobb et al., 2016) and face a high risk for posttraumatic stress disorder, including anxiety, depression, stress and grief (Alfheim et al., 2019; Davidson et al., 2012; Haines et al., 2015).

Research indicates that families of ICU patients have three areas of support needs (Khalaila, 2013; Nagl-Cupal et al., 2012; Olding et al., 2016). First, they need ongoing, clear and consistent information about the patients' condition and prognosis, particularly so when decisions about treatment withdrawal need to be made and a shift from curative interventions to palliation occur within a short time-frame (Kisorio and Langley, 2016; Nelson et al., 2010; Wong et al., 2015). Second, families want to be present and close to their critically ill family member and partake in the planning and decision-making around care and treatment (Blom et al., 2013; Noome et al., 2016; Vandall-Walker and Clark, 2011). Third, family members require support for dealing with difficult emotions, uncertainty and stress, for mobilising resources to live through the event and its aftermath; and eventually for making meaning of the critical illness and death (Cypress, 2011; Frivold et al., 2016).

ICU staff play a vital role in meeting those needs during a patients' ICU stay (Adams et al., 2014; Au et al., 2019). Research has identified a general openness of ICU staff towards families (Al Mutair et al., 2014; Kean and Mitchell, 2014) and sound knowledge of family needs (Buckley and Andrews, 2011). However, unsupportive ICU environments and culture (Kleinpell et al., 2018; Vandall-Walker and Clark, 2011), lack of staff skill in family communication and shared decision-making (Khalaila, 2013; Rusinova et al., 2014) and inconsistent delivery of family involvement and support in ICU (Buckley and Andrews, 2011; Hetland et al., 2018; Kleinpell et al., 2019) have also been reported.

Because insufficient family engagement and support has been linked with family distress during and adverse psychological health after ICU care (Carlson et al., 2015; Frivold et al., 2016; Hwang et al., 2014; Khalaila, 2013), best practice recommendations include that ICU teams enable family presence and involvement, communicate with family members using a structured approach, offer psycho-educational family support and incorporate specific consultations and family navigators into the delivery of care (Davidson et al., 2017; Gerritsen et al., 2017). However, research evaluating such models of family care in ICU has been scarce (Shelton et al., 2010; Torke et al., 2016; White et al., 2018; White et al., 2012). The evidence of these recommendations around complex family interventions (Davidson and Strathdee, 2019) warrant further substantiation. In particular, an in-depth understanding of both family members' and health professionals' experience with and acceptability of nurse-delivered, family support interventions is needed. Hence, we investigated family and health professional experience with a new model of care, which consisted of an advanced practice family nurse coupled with an interprofessionally-delivered family support pathway. The new model of family care was introduced as part of a quality improvement initiative in one surgical-transplant ICU with the aim to better address family need for proactive engagement, consistent and constant communication and emotional and practical support during critical illness. Such an approach became necessary as the ICU team was increasingly confronted with complex, psychosocial care needs of families with diverse cultural backgrounds and constellations, coupled with long-lasting care situations of persons with pre-existing chronic illness. The aims of the study reported here were first, to gain an in-depth understand of families' experience of using the service and their perception of benefit and second, to identify health professionals' experience of implementing a new model of care and delivering care to families with the new model of care in place.

Methods

Design

We conducted a qualitative evaluation study using content analysis strategies (Graneheim et al., 2017; Graneheim and Lundman, 2004; Patton, 2014). This qualitative study was part of a larger mixed method research project investigating the mechanisms of impact as well as the outcomes of the nurse-led family support intervention on family satisfaction with care and well-being. Qualitative evaluation of intervention outcomes and processes, including users' and providers' experience with using and delivering the intervention and their perception of the intervention's impact on quality of care, is essential to build research evidence around how complex interventions work in practice (Moore et al., 2015; Morgan-Trimmer and Wood, 2016). Qualitative research thereby complements evidence generated from intervention trials (Craig et al., 2008).

Setting, Participants, and procedures

The study took place in a 12-bed surgical-transplant ICU at a major, 900-bed University Hospital in Switzerland. Family members were defined as close others from the patient's perspective. Participants had to be 18 years or older, cognitively able to understand and take part in the study as appraised by recruiting staff and able to speak German. Only those who had received at least one intervention from the family nurse (≥five minutes) were approached. Those with self-reported mental illness were excluded. Health professionals had to be working in the study ICU for at least six months. No exclusion criteria were applied.

Consecutive, purposive sampling for the qualitative part of the study started after the family support intervention had been implemented and running for three months. From that timepoint onwards, all family members meeting the inclusion criteria were invited to participate in the interview part of the study by the advanced practice family nurse upon concluding care. If they expressed interest, in addition to the entire study information pack, they received written information about the interview component of the study. One researcher (RN) then actively contacted each family member to invite participation, answer questions about the study and obtain oral consent. An interview date, mode and location was set according to participants' preferences. Before the interview, family members signed a written informed consent and completed a brief demographic questionnaire.

A purposive strategy was used to invite ICU staff with the aim to ensure representation of different roles. A total of 31 ICU nurses (from 65) and three physicians (from 14) were personally invited by email. A study flyer was also displayed in the staff lounge to invite those interested to take part. Verbal consent was obtained from each health professional before taking part in the focus groups, upon which they signed a written informed consent.

Decisions around sample size were guided by considerations around heterogeneity of the sample, completeness of data to answer the research question, and recurrence of themes in the interviews and focus group narrations around participants' experience with the intervention (Creswell, 2013). A sample size of 15–20 participants is generally considered adequate for qualitative evaluation research using interviews (Baker and Edwards, 2012; Patton, 2014). Three to four focus groups is necessary to generate enough data to answer a research question (Guest et al., 2017; Morgan, 1997/2013).

Family support intervention

The new model of family care was introduced in September 2018. The aim was to increase family well-being and experience with ICU care, to alleviate family suffering due to critical illness, and to reduce the negative consequences of critical illness and / or loss on family members' mental health. It also aimed to support ICU nurses and physicians in caring for families. The intervention targeted primarily families whose critically ill close other was admitted with a life-threatening condition or expected to stay longer than two days. An advanced practice nurse (APN) with certification in ICU nursing and training in family systems care delivered the family support intervention in close collaboration with ICU nurses and physicians along a standardised family support pathway (see Fig. 1).

The APN-delivered family support intervention was based on a relational, systemic and strength-based approach to family nursing care (Doane and Varcoe, 2005; Gottlieb, 2012; Wright and Bell, 2009; Wright and Leahey, 2013) and advanced practice role framework (Bryant-Lukosius et al., 2016; Hamric et al., 2014; International Family Nursing Association, 2017). It was informed by ICU team expertise, which was obtained through two team consultation, as well as by evidence and best practice around ICU family care (Al Mutair et al., 2013; Davidson et al., 2017; Goldfarb et al., 2017; Linnarsson et al., 2010; Olding et al., 2016). The APN intervention entailed three components. First, relational, family systems nursing interventions, which consisted of nurse-therapeutic family conversations that aimed to strengthen family coping and illness management. Second, liaison and collaborative care to increase ongoing communication and interaction between the family and the ICU team. Third, early, proactive family engagement over time, starting upon admission and stretching several days, or, in the event of loss, several weeks into the post-ICU phase. Frequency and duration of APN intervention contacts with families, while standardized along the patient pathway, differed depending on families' needs and patients' length of ICU stay. APN family interventions were offered in addition to shift or primary nurse support at the bedside and interprofessional family meetings.

Data collection

Individual and dyadic interviews: Sixteen individual or dyadic interviews were conducted by the first author with families between February 2019 and July 2019. To capture families' entire experience with the support intervention, interviews were held after the conclusion of the family nurse's follow-up care, either over the phone or at a place of participants' choice. Semi-structured interviews are a useful way of collecting data when individual and family perspectives and views are of interest (Benzein et al., 2015; Patton, 2014). Both individual and dyadic interview formats were held to offer family members a choice. Interviews started with an invitation to describe the family experience of ICU care and entailed questions such as "What was your experience of receiving the intervention?", "What was helpful, and what was less helpful"?, "How, if at all, impacted the care you received on your ability to manage as a family experiencing critical illness?" Field notes were written to reflect on the research-family interaction and gathered data.

Focus group interviews: Three focus group interview were held with nurses and physicians, with six to seven participants each. One focus group was held in January 2019 to monitor experience with implementation and delivery, and two in July 2019 to evaluate processes and outcomes of the intervention as experienced by staff (Barbour, 2014). Focus groups generate interactive data on shared experiences, practices and cultures by bringing persons in similar situations together, and a particularly useful in health services and implementation research (Jayasekara, 2012; Onwuegbuzie et al., 2009). Two researchers who did not know participants co-moderated, using an interview guide. Questions included, for example: "How do you experience family care since introducing the new service?, "How do you experience service delivery and collaboration with the new role?"; "What benefits, if any, do you experience yourself or see in families?".

Data analysis

Audio-recorded interviews were transcribed by a professional transcriptionist, controlled for accuracy and entered into NVivo (https://www.qsrinternational.com/nvivo), a qualitative data analysis software used to organise and manage data analysis. To identify patterns of meanings in the data, we used inductive content analysis as described by Graneheim and Lundman (2004) and specified by Erlingsson and Brysievicz (2017). Inductive content analysis is a systematic process of abstracting textual data, moving from more manifest content to the interpreted, latent meaning of the

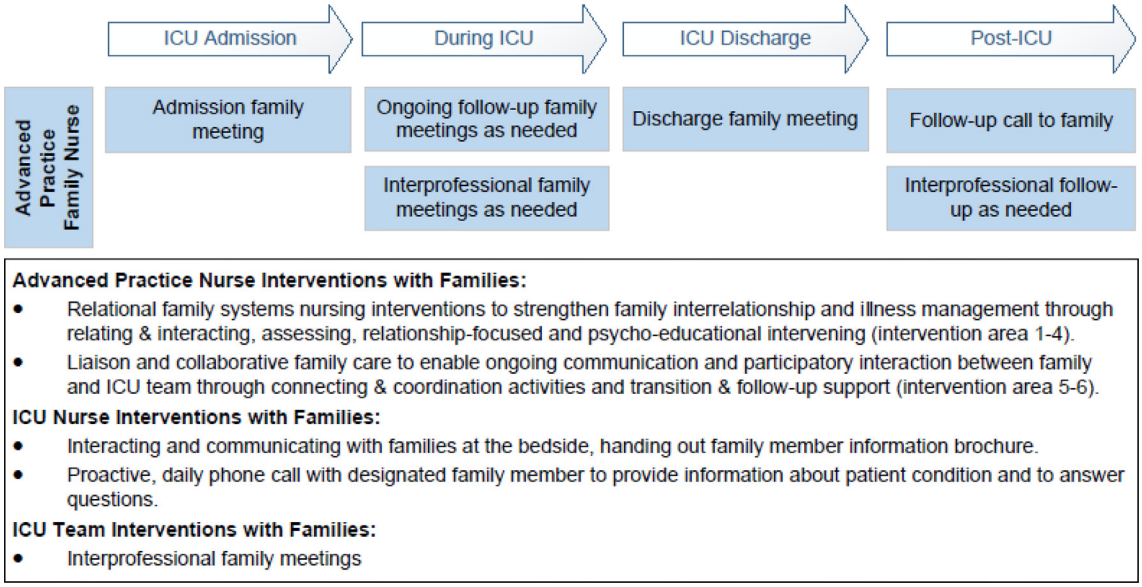

Fig. 1. Family support pathway with APN interventions.

text through a series of analytical activities (Elo and Krngäs, 2008; Graneheim et al., 2017; Vaismoradi et al., 2013). Analytical steps include the identification of meaning units, the labelling of these meaning units with codes, the grouping of codes into categories, and eventually the creation of themes (Erlingsson and Brysiewicz, 2017; Graneheim and Lundman, 2004). Family and health professional data were first analysed separately until the level of categories and then collated into common themes.

First, transcripts were read and reread to get a sense of the whole by two researchers, and first interpretive insights were written down. Then, meaning units; that is, sentences that carry relevance in relation to the research question were identified, condensed and then coded. Codes were grouped into collated codes and further abstracted into sub-categories and then categories, first with family member data and then with health professional data. Categories from both data sets were displayed together, compared and contrasted, and then synthesised into common themes. Interpretive and reflective writing occurred at each analytical step, which helped to refine the findings structure and capture interpretive insights.

Rigour of the study

To ensure study rigour, strategies to establish trustworthiness that are specific to content analysis were used (Elo et al., 2014; Graneheim et al., 2017). First, data were gathered after careful preparation by three experienced, doctorally-prepared nurse researchers not involved in intervention delivery. Data collection continued until the available data became redundant and confirmatory. This occurred through interpretive writing and discussions among the researchers involved in data collection. Analysis was conducted by two researches with training in qualitative methodology using a recursive process of increasing abstraction and interpretation of the data and regular interpretive meetings. To ensure rigour of the analysis process, ongoing reflections on researcher-participant interactions, emerging insights and analytical decisions were noted in an audit trail. Findings were verified by contextualising themes in the data through the use of quotes.

Ethical consideration

The study was submitted to the Ethics Committee of the Canton of Zurich, which waived the need for approval (Req-2018-00107) based on national law. We followed the national guideline of Research with Humans (Swiss Academy of Medical Sciences, 2015).

Findings

Participant characteristics

Thirty-eight people participated (50% family members, 45% ICU nurses, and 5% ICU physicians). Of the 58 families who had received the intervention, we invited 36 families for an interview and 16 families, represented by 19 family members, participated (45% response rate). Fifteen families declined participation due to high caregiving burden or fear of 'stirring their emotions up' and five would have liked to take part, but did not find the time to do so. Family member participants were predominantly women and half had experienced the loss of their close other (table 1). Interviews had a median length of 26 minutes (range 35) and took place over the phone (37.5%, main reason was long distances) or face-to-face at family members' home (31.2%), at the hospital (18.8%) or a public place (12.5%).

Nineteen of the 31 invited health professionals (62% response rate) participated in one of the three focus group interviews (n = 17 nurses, n = 2 physicians). Reason for non-participation were no time or conflicting schedules. Health professionals were mostly ICU-trained, experienced nurses (Table 2). Focus groups lasted between 61 and 68 min and took place at a meeting room at the hospital.

Table 1
Family member characteristics.

Family members	**n = 19**
Age median (range)	52.5 (51)
Female gender n(%)	15 (78.9)
Civil status n(%)	
married, partnered	12 (63.2)
divorced, separated	2 (10.5)
single	4 (21.1)
widowed	1 (5.3)
Own children, yes n(%)(n = 18)	12 (66.7)
Education n(%) (n = 18)	
vocational training	4 (22.2)
diploma / degree	10 (55.6)
postgraduate degree	4 (22.2)
Employment n(%)	
employed	14 (73.8)
retired	2 (10.5)
unemployed	2 (10.5)
other (students, working at home)	1 (5.3)
Distance home-to-hospital n(%)	
Same city as hospital	1 (5.3)
Outside city	8 (42.1.4)
Outside canton	10 (52.6)
Relation to patient n(%)	
child	8 (42.1)
parent	4 (21.1)
spouse	3 (15.8)
sibling	2 (10.5)
other family member	2 (10.5)
Co-habiting with patient before admission n(%)	7 (36.8)
Frequency of contact with patient before admission* n(%)	
Several times a week	7 (58.3)
Once a week	2 (16.7)
Once a month	1 (8.3)
> once a month	2 (16.7)
Critically ill person	**n = 16**
Age median (range)	60.5 (65)
Cause of admission n(%)	
unplanned	10 (62.5)
transfer from other ICU	4 (52.0)
organ transplant	2 (12.5)
Length of ICU stay median (IQR)	11.5 (7.0, 20.0)
Died in ICU, yes n(%)	10 (52.6)
Intervention characteristics	**n = 19**
Number of intervention contacts m(SD)	4.9 (1.75)
Duration of intervention per LoS in minutes** m(SD)	15.5 (15.9)

*only family member who are not co-habiting with the critically ill person: interview participant n = 12.
** LoS = Length of Stay.

Thematic findings

Four themes common to family members' and health professionals' narrations of their experience with the APN-led family support intervention were identified. They pertained to two domains: their experience with the intervention and advanced practice family nursing role (process-oriented themes) and their experience of benefit (outcome-oriented themes). The overview of the four themes with quotes are displayed in Table 3.

A valuable, essential part of ICU care (first process-oriented theme)

Family members and health professionals described the family support intervention as a fitting and acceptable service that is com-

Table 2
Health professional characteristics.

Health professionals	**n**	
Age median (range)	19	36.0 (32)
Female gender n(%)	19	16 (84.2)
Training n(%)		
registered nurse with ICU certification	19	15 (79.0)
registered nurse		2 (10.5)
physician with ICU speciality training		2 (10.5)
Years of professional experience, median (range)	17	13.0 (38.0)
Years of ICU experience, median (range)	18	7 (36.0)
Own experience of serious illness as family member, yes n(%)	18	9 (50.0)
Training in family care, yes n(%)	18	1 (5.6)
Self-perceived proficiency in family care (FNPS*) median (range)	10	2.25 (2.10)
Attitudes toward families in care delivery (FINC-NA+) median (range)	11	62 (19)

* FNPS = 10-item German version of the Family Nursing Practice Scale, score ranges from 0 (high proficiency) to 5 (low proficiency)
+ FINC-NA = 19-item German version of the Families' Importance in Nursing Care-Refined scale, score ranges from 19 (very negative attitudes) to 95 (very positive attitudes).

plementary to the care they receive from ICU physicians and nurses responsible for patient care. Families highly appreciated the attention to and focus on their well-being (Table 3, quote 1a). Of particular importance was that the care they received through the support intervention was not taking away nurses' time and effort from their critically ill family member (1b). While their need for support varied, families stressed the importance of the availability of such a service for families experiencing critical illness (1c).

Health professionals unanimously experienced the family support intervention as a beneficial addition to the care they provided to family members at the bedside. They saw the APN-delivered services as complementary to their own care (1d), and as a specialised form of family nursing that required specific knowledge about family processes and skills in supporting family interrelationships and everyday coping (1e). As such, health professionals experienced the new role of an advanced practice family nurse as a valuable supplement to their interprofessional team (1f).

A person who facilitates staff-family interaction and communication (second process-oriented theme)

For participants, the APN was a liaison person who facilitated interaction between the patient, the family, and ICU staff. As the APN was an ICU-trained nurse and part of the ICU team, she was knowledgeable about the critically ill family member, expected course of illness, and ICU treatment modalities (Table 3, quote 2a). Families experienced the APN as a person who they could turn to for advice and support whenever they felt they needed it (2b). While not around every time the family visited, they experienced the APN as highly accessible through phone, email, and the nurses at the bedside.

For health professionals, the APN acted as an intermediary. She was described as a "*communication pipe*", a "*spider who webs the net of care*", or who weaves a "*red thread*" of family care. The continuous interaction of the APN with families facilitated mutual communication and understanding among families and the ICU team (2c). Furthermore, The APN took charge of coordinating the care that families needed and ensured a continuous process of care (2d) that enabled nurses and physician to follow and participate in care provision to families in a meaningful way (2e).

Promoting quality of family care (first outcome-oriented theme)

Families and health professionals perceived the quality of ICU care to be high with the new model of care delivery. Family members experienced ICU staff as attentive towards their situation and needs (Table 3, quote 3a). They appreciated the available services of receiving a phone call by the shift nurse to inform them about their critically ill members' condition every morning (3b). Family members felt reassured that the medical and nursing care that their family member received was the best possible, and felt that their family member was always in safe hands (3c).

Families experienced a relational partnership and interaction with the family (3d). They appreciated her unobtrusive presence and described her as "*calm*", "*empathic*" and "*knowledgeable*". Families experienced the emotional and practical support as helpful and meaningful (3e). Examples of family nurse interventions received by families included offering presence, therapeutic listening and conversing, providing information and education, organising practical support (such as a place to sleep, a parking voucher), referring to additional services, connecting to bedside nurses and physicians and following-up with families after the ICU stay.

Health professionals stressed that families' needs could be better met since the support intervention had been implemented. They experienced families as better prepared and informed, and calmer when visiting their critically ill family member (3f). The APN family interventions were perceived as supporting family coping with the critical illness (3g), fostering family cohesion (3h) and promoting family decision-making around the plan of care (3i).

Enabling ICU staff to better care for families (second outcome-oriented theme)

Health professionals described more effective relationships with families after implementation of the support intervention. This occurred through better knowledge of the family situation and needs (Table 3, quote 4a), which was generated by the advanced practice family nurse through her assessment of the family structure, resources, preferences and needs, which was then communicated and documented (4b). This knowledge meant that nurses could engage families in more purposeful ways (4c) and became better in managing their encounters with families at the bedside (4d).

Health professionals vividly described ways in which the APN-led family support intervention was helpful and supportive to them. Nurses (4e) and physicians (4f) felt supported in their daily work with families and experienced more effective care provision to families. Nurses also felt an ease in their workload (4g). The advanced practice family nurse ensured sufficient capacity for patient and family needs in life-threatening situations. She also offered emotional and practical support to families, otherwise the task of the primary and shift nurses, who did not always feel able to offer this kind of care (4h). Physicians appreciated the support during family conversations (4i). Knowing that the family nurse was around and available meant that nurses (4j) and physicians (4k) felt reassured that families are looked after. Nurses and physicians experienced less moral distress, caused by situations of being unable to respond to family needs due to lack of capacity during moments of great family need.

Discussion

The study, which is part of a larger mixed-method study, investigated family and health professional experience with using a newly implemented, evidence-based model of family care in one surgical-transplant ICU. The study demonstrates that the role of

Table 3
Thematic findings.

Themes	Categories	Sub-categories illustrated with quotes
A valuable, essential part of ICU care	**An appreciated, fitting and necessary intervention (family)**	*An intervention that is highly appreciated.* 1a) The whole thing was great. You're there, you're lost, you don't know what to do, you have fears, well, in one day, everything is gone, (and you don't know) what is happening. And then, after all, you do have someone who is a bit rational, but who is also emotionally present. Right, who doesn't play down a tape, but who responds to the emotions people have (daughter ID 565) *An intervention that does not take away staff attention from patient care.* 1b) She came, well, this was very special to us because we had this sense of: "Now it is really only about us and we don't have to hurry up because…" With the others, you do not want of course to keep them from their important work (with the patient). That was a very good experience (daughter, ID 574) *An intervention that is vital to ICU care.* 1c) I believe it is a very important part of (ICU) care, besides the patient and all that. Families are really a big part of it (sister-in-law, ID 578).
	An added value and needed component of ICU care (staff)	*Family nurse offers complementary and specialized family care.* 1d) When (the family nurse) is at the bedside (with me), as a human being, it is enormously valuable. I am really… most of the time I am busy with something. I can't meet (families' needs) at the bedside. Certainly not as comprehensive as (the family nurse) provides support. Or any support at all that is focused on the family (nurse, fg3 +). 1e) It has really proved its value, I have to say, very much so. I experience her work as very, very worthwhile. Some of us do it along the same line, but not with so much depth as (the family nurse) does, she really takes it a step further. (…) She takes a different starting point because she has trained for it (…), she has different thoughts and she has time for these ideas in a way we do not (nurse fg3) *Family nurse is a valuable team member.* 1f) I believe that for our team it is… Well, with her personality, (the family nurse) succeeded to get a foot into our team, well to set a foot into our door permanently. With her work and the way she familiarized us with it (nurse, fg2).
A person who facilitates staff-family interaction and communication	**An easily and reliably accessible person who is part of the ICU team (family)**	*Family nurse is knowledgeable about patient.* 2a) She was able to give us information about my brother, for instance when we did not understand something. And conversely, she could ease our worries (…). She was someone who took an interest, right (sister, ID 538) *Family nurse is available from admission to discharge and beyond.* 2b) It was more a humanistic approach from someone who takes an interest. With whom you know you can talk about something else (i.e. not medically-related) for a bit longer, right (…). She was more or less around. Someone always knew, well (the family nurse) will be with you shortly, or we will be able to ask her when (she is in again)… We often said to each other: If everything else fails, we ring her up (daughter, ID 567).
	A continuous facilitator of communication and coordinator of family care (staff)	*Family nurse facilitates communication.* 2c) Well, she follows up (with families) and I noticed that she uses a totally different language to do so, which is much closer to the person… and that results in new opportunities to understand families (…). Well, she would repeat something in different words. And you do see how that relieves families. We can then clarify and say: "Yes, that is how we meant it and that is what we worry about". You really can't fail to notice how that supports families, enormously. But also for us, for our part, well, I've also come to realize that she may have to translate something that is difficult to grasp for families, what was meant with a particular term. She is like an intermediary somehow (physician, fg3). *Family nurse coordinates care for family.* 2d) Physicians change, we change, we have different shift plans and at some point you run up against it and you have a déjà vu and ONLY then things started to get into motion. And now, I've seen it play out differently. Someone would say: "Well, let's do a follow-up family meeting, we have to get together. We need a round table, and we need other specialists at the table. And we had someone who was around to organize it and who was creative enough to say: "We will need to include this person too". (…) We have more family meetings, not just one single one sometime, but consecutive ones, which means that we have a process during which decisions can be made (nurse, fg2). 2e) I think it is very important to have someone who is practically always and continuously around. Who can build on something ALL THE TIME. (…) Because when you set a meeting right away you can draw a bow and you have the opportunity to look back and see what has happened. That is a great help (nurse, fg3).
Promoting quality of family care	**Being well looked after by entire ICU team (family)**	*Entire ICU team and care structures are attentive towards family.* 3a) Staff was very attentive towards us. Each time. You can really say that. You saw that they were prepared when we came in the manner in which they approached us. We appreciated this every single time. And they've also asked us if we wanted something to drink. They came from time to time and offed us something to drink (father, ID 526). 3b) They called when something was up. And we could call them anytime, when we were unsure or such, you could ask anytime. The daily morning call was a real good thing. You get a call even when everything is normal and that helps. Well, by normal I mean, when the situation is stable, right (mother, ID 540). *Critically ill family member is in safe hands.*

Table 3 (*continued*)

Themes	Categories	Sub-categories illustrated with quotes
		3c) Well, we can't stress that enough – we were SO well looked after, we really were. We also knew that our father is in safe hands there (daughter, ID 524). Well, he was, how should I say, cared for to the best of their knowledge (daughter, ID 537). *Helpful relationship with and support from family nurse.* 3d) And most of all, she is a person who it is easy to get along with. She comes across as someone, well you are immediately, well, I immediately felt familiar and at ease with her. (. . .). Like a peer, on equal footing, I am not sure how to best express it. At eye-level really (mother, ID 522). 3e) She was simply around. In an unobtrusive way. They did not intrude. But, again and again: "We are here for you. We are". Well, yes, "Please come to see us if you have questions or concerns". Well, I personally, would have been flat on my back (without it). Yes, she was able to give me a lot – she was present for me, right (daughter, ID 524).
	Families are better cared for (staff)	*Comforted and calmer families.*3f) Family members are calmer because they are better informed, in a more structured way, not just bits and pieces from everyone. As a consequence, they ask less if they can speak with a physician, which we then have to organize. They have a person to turn to and they have the information they need. (. . .). I have not seen situations that escalate anymore, not really. I mean people have reacted to losses and they have had outbursts or they cried, but no. . . there were no personal assaults or aggressions (nurse, fg1). *Informed and supported families.*3g) I believe most family members really felt that their needs were met. They could voice their fears and worries and their questions (with the family nurse) in a way that they probably did not dare to do with us. But they did talk about it with (the family nurse) and still knew that we would learn about it, which was okay for them. (They also knew that) one person will take care of their needs and concerns (nurse, fg2). *Family cohesion and decision-making is fostered.* 3h) My experience is that families are more united and can act together as a family. They are like invited to go through this experience together. They were more conscious of. . . that they don't have to go though it alone, but that they could do it as a family. . ., of the resources they have to cope with the situation. It was pointed out to them and that they may cope better when they stick together (nurse, fg2) 3i) And well, they were able to find a consensus within the family, if that is the word. So that everyone is on the same page and knows what the treatment aim and plan of care is (nurse, fg3)
Enabling ICU staff to better care for families*	**More effective relationships with family (staff)**	*An increased understanding of family situation and needs.* 4a) It makes it easier sometimes to appreciate the situation and family members' decisions. (. . ..) It is helpful when you know who is connected with whom and what he or she is doing in life. A bit like a biography, which helps me to get an understanding for the situation (nurse, fg2). 4b) She (family nurse) had a conversation with the family. When you read her notes you are immediately up to date and you know exactly: "Ah, that's what the family is concerned about" (nurse, fg1). *Constructive, purposeful interactions with family.* 4c) When I am up to date, I have a good access point with the family, I can show them: "Hey, that's. . . I know about this, we are aware about this, and we don't need to start from scratch and run from pillar to post" (nurse, fg3). 4d) I really have the impression that family members are more open to ask things at the bedside, even when (the family nurse) is not around. They are assured to ask. Before, they were more reluctant and may not have wanted to burden us or they may not have known what to ask for. I really feel that they can open up. It is a bit easier to engage them in a conversation, that's my impression (nurse, fg2).
	Reassuring for ICU staff (staff)	*A support in everyday working with families.* 4e) Particularly in situations in which I realize that I do not have the chance to tackle the problem, the situation or the resources, well, to draw forth positive resources. Well then, someone is around who knows what to do, and that is a real support (nurse, fg2). 4f) She's alongside the family, you sense that really clearly. Of course you talk about the patient and about the medical condition, but you always also need to know what is happening in the family and that is really complex, and in that, she is a huge pillar of support. (. . .) From my point of view, as a rule, she is available in those moments in which you need her, because she is following the case herself. She makes an active contribution, and as a physician, you're really supported. *An ease of workload.* 4 g) I do appreciate (that she takes care of family members) because I can take care of those things that really matter and which are central to my mandate, and that is the patient. It makes my work much easier (. . .). If I'm assigned to a patient who is in a very critical situation with circular instability and all that, she takes it off me and I do not need to organize support. That is plainly spoken my gain (nurse, fg1). 4 h) I like it because I can hand over parts of my work. This mean that I do not have to stress myself with those things. I do not have to consult the social worker, I do not have to run after that. (The family nurse) organizes it all. And that is, for us, it eases our workload (nurse, fg3).

(*continued on next page*)

Table 3 (*continued*)

Themes	Categories	Sub-categories illustrated with quotes
		4i) It is a big relief because as physicians, we often have to inquire about the decisions, some, yes, as you stressed, we have to do those family conversations under time pressure (physician, fg3). *An alleviation of distress.* 4j) I don't have to worry all the time while working at the bedside: "Is anyone speaking to the family? They are already waiting for two hours and there is no end in sight to this situation". And mh, forasmuch, she can intercept and compensate such situations very, very well (nurse, fg2). 4k) It is not a relieve in that sense for us. Except for your conscience, because you think: "Ah, that's good, someone is taking care of the family, so I do not have to (go and seem them) again". That is not to be underestimated. It does not sound very well for us physicians, a bit negative, really: But my need really only is that I am relieved when I do know that someone is taking care of the family (physician, fg1).

[+] Focus group.
[*] Family member experience of benefit from the nurse-led family support intervention is reported elsewhere.

an ICU family nurse practicing at an advanced competency level of family systems nursing is acceptable to families and ICU staff alike. Coupled with an interprofessionally-delivered family support pathway, it denotes a highly appreciated model of care delivery that is able to respond to and meet their respective needs for support. We also found that family members and health professionals concurred in their perception of benefit for the quality of ICU care. Remarkably, no negative experiences were described. It may well be that participating family members and health professionals did not have any negative experiences with the new model of care or did not express them.

Many of the ICU-specific roles that help families to navigate critical illness and ICU care are held by nurses or social workers, and focus on information provision, communication and decision-making support (Curtis et al., 2016; Shelton et al., 2010; Torke et al., 2016; White et al., 2018). We based our intervention on a relational, family systems approach to care (Bell, 2009; Östlund and Persson, 2014) and advanced nursing competencies (International Family Nursing Association, 2017), adding therapeutic nurse-family conversations to communication and coordination activities. These included active listening, circular questioning, drawing forth inner-family resources, communicating and educating and counselling around coping with critical illness Previous research reports high acceptability of a comparable nursing role from families (Torke et al., 2016). In our study, participants described the advanced practice family nurse-delivered support intervention as a highly appreciated and meaningful part of ICU care that complemented pre-existing responsibilities within, and care offered by an ICU team with a specialised, yet integral service. Families stressed the importance of having a knowledgeable, competent, and empathic person available to them, who is part of the ICU team, but not taking away time and attention from patient care activities. Skilled ICU staff that is attentive to families' situations and needs has previously been found to be important to families (Blom et al., 2013; Frivold et al., 2015; Kodali et al., 2014). However, research to date has found that families are not consistently involved and engaged in care, and do not always receive the support they need (Carlson et al., 2015; Hetland et al., 2018; Kydonaki et al., 2019). Heavy workload, lack of nurse skills, views of families as outsiders and interruptions to workflow, or a lack of leadership and organisational support are known barriers to family engagement in care for meeting their needs. (Hamilton et al., 2020; Hetland et al., 2018; Kleinpell et al., 2018). Hence, a specific family nursing role that ensures ongoing communication and interaction with families, supports family coping with critical illness, and helps them to navigate the complexities of ICU care and decision-making, might play an important part in ensuring consistent and participatory family engagement in ICU, and in reducing families' burden of critical illness (Ågren et al., 2019; Curtis et al., 2016; Daly et al., 2010; Moore et al., 2012).

Our model of care was comparable to similar initiatives that aim to increase quality of communication, support and care coordination in ICU, particularly for surrogate decision-makers (Moore et al., 2012; Seaman et al., 2018; Torke et al., 2016; White et al., 2018; White et al., 2012). Such models of ICU care have been found to be beneficial for family satisfaction with ICU care (Goldfarb et al., 2017; Moore et al., 2012; Scheunemann et al., 2011; Shelton et al., 2010; White et al., 2018). Our study differs in that we employed an ICU trained family nurse with advanced competencies in family nursing that offered systemic family interventions (Wright and Bell, 2009; Wright and Leahey, 2013). In our study, families experienced the interactions with the family nurse as engaging and helpful, reported to be well looked after, and felt reassured that all members of the family, including the critically ill member, received the best possible care. Both families and health professionals reported a high quality of

ICU family care. An advanced competency level seems to be useful since this enabled relationship-based, systemic family nursing interventions that have been shown to be beneficial in supporting family interactive coping and chronic illness management (Chesla, 2010; Hartmann et al., 2010; Östlund and Persson, 2014; Thirsk and Moules, 2013), but has scarcely been investigated in the ICU setting (Ågren et al., 2019; Chaboyer et al., 2007).

Evaluations of family support interventions with health professionals remain scarce. For health professionals in our study, the family nurse acted as communication facilitator who connected the dots and coordinated delivery of family care. Hence, our findings reflect best practice recommendations for family-centred ICU care, which stress the need to introduce specific consultation roles into the provision of ICU care to families (Davidson and Strathdee, 2019; Gerritsen et al., 2017). Health professionals observed a beneficial impact on families. Study participants perceived families to be calmer and more empowered to live through the critical illness and to make decisions as a family compared to their experience of families before implementation of the family nursing role and pathway. They also found that the implementation of a new role increased the quality of communication with families, and improved coordination and continuity of care provided to families. This is in contrast to one of the few studies that investigated nurses' and physicians' perception of quality of communication, decision-making processes and satisfaction with ICU care following implementation of a new role, which did not identify any statistically significant changes (C. D. Moore et al., 2012). It is difficult to interpret the divergences of findings, but one reason might be that our qualitative assessment allowed for more nuanced descriptions of changes in practice. More research is needed that attends to the impact of nurse-led family support interventions on the processes and outcomes of ICU care.

To our knowledge, this is the first study to investigate health professionals' perception of benefit of a family support intervention for their own clinical work. ICU nurses experienced the presence of a family nurse who provided information and support to families in acute crisis and over time as relieving in terms of workload but also in relation to moral distress. ICU staff have reported a lack of confidence and competence to care for families as well as an inability or lack of capacity and structural support to address families' needs, leading to role conflicts (Hetland et al., 2017; Shariff et al., 2017; Stayt, 2007). This tension was also evident in our study. Following implementation of the new model of care, ICU nurses and physicians experienced an augmented ability and capacity to care for families. They reported that their understanding of families' situation, impact of critical illness and family needs increased through the family nurses' interactions with families. As a result, relationships with families became more effective. Increased interaction, mutual understanding and shared decision-making is key to family-centred ICU care (Mitchell et al., 2016) and for achieving positive health outcomes (Goldfarb et al., 2017).

Strengths and limitations

The qualitative evaluation study triangulates data from family members and health professionals. A sample size of 38 participants and 19 individual, dyadic or group interviews yielded comprehensive, redundant and confirmatory data on the experience with and benefits of an ICU family support intervention (Baker and Edwards, 2012; Guest et al., 2017). However, the study is not without limitations. Physicians were under-represented in the health professional sample. Findings therefore rely predominantly on ICU-trained nurses' perspective. Moreover, the lack of reported negative experiences with the new care model of care may be the result of our inability to recruit participants who did not find the interventions to be supportive. Some family members did indeed prefer not to take part in an interview due to lack of time or out or fear to be overwhelmed by upsetting memories and emotions. It might well be that their experience may differ from those who agreed to participate. Hence, it is possible that our findings do not capture the full range of experience with the family support intervention. Data were collected in one surgical ICU only, which limits the transferability of the findings to other ICU settings and hospital contexts. This study is in line with recommendations made within the MRC framework for feasibility and pilot-testing of complex interventions (Craig et al., 2008; Moore et al., 2015), and the need to use process evaluation and qualitative approaches to increase understanding of intervention processes and outcomes (Curry et al., 2009; O'Cathain et al., 2013). While this study demonstrated acceptability and value of the family support intervention, multi-centre, controlled testing is needed to establish the family support interventions' effectiveness in improving quality of care and on family member health outcomes.

Conclusion

We found that an advanced practice family nursing role coupled with a family support pathway is an acceptable, appreciated and beneficial model of care delivery from the perspective of families, nurses and physicians. Family and health professional data that were gained through individual, dyadic and focus group interviews corroborated each other, providing a consistent and comprehensive, qualitative understanding of the experience with and benefit of the nurse-led family support intervention. While more research is needed, our study suggests that a specialised family support role has the potential to improve quality and efficiency of care provided to families of critically ill persons, and increase ICU teams' capacity and ability to meet families' needs. Our study contributes to an evolving evidence base around the beneficial impact of family support interventions on satisfaction with and quality of patient and family care (Goldfarb et al., 2017). Further research is needed to better discern the mechanisms through which family support interventions achieve their desired benefit and to determine intervention effectiveness on family mental health.

Ethical statement

The study was submitted to the Ethics Committee of the Canton of Zurich, which waived the need for approval (Req-2018–00107) based on national law. The study was conducted according to Swiss guideline for research with humans. All participants received a study information pack and more than 24 h of time to make a decision about participation. All participants signed a written informed consent before taking part in an interview.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Authorship statement

RN, PM and HP designed the study, RN collected the data, RN and HP analysed the data, and PM contributed to the interpretation of the data. RN wrote the first draft. All authors have revised the article critically for important intellectual content and have approved the final version.

References

Adams, J.A., Anderson, R.A., Docherty, S.L., Tulsky, J.A., Steinhauser, K.E., Bailey Jr, D. E., 2014. Nursing strategies to support family members of icu patients at high risk of dying. Heart & Lung J. Acute Critical Care 43 (5), 406–415. https://doi.org/10.1016/j.hrtlng.2014.02.001.

Ågren, S., Eriksson, A., Fredrikson, M., Hollman-Frisman, G., Orwelius, L., 2019. The health promoting conversations intervention for families with a critically ill relative: A pilot study. Intensive Crit. Care Nurs. 50, 103–110. https://doi.org/10.1016/j.iccn.2018.04.007.

Al Mutair, A.S., Plummer, V., O'Brien, P.A., Clerehan, R., 2013. Family needs and involvement in the intensive care unit: A literature review. J. Clin. Nurs. 22 (13–14), 1805–1817. https://doi.org/10.1111/jocn.12065.

Al Mutair, A.S., Plummer, V., O'Brien, P.A., Clerehan, R., 2014. Attitudes of healthcare providers towards family involvement and presence in adult critical care units in saudi arabia: A quantitative study. J. Clin. Nurs. 23 (5/6), 744–755. https://doi.org/10.1111/jocn.12520.

Alfheim, H.B., Hofso, K., Smastuen, M.C., Toien, K., Rosseland, L.A., Rustoen, T., 2019. Post-traumatic stress symptoms in family caregivers of intensive care unit patients: A longitudinal study. Intensive Crit Care Nurs 50, 5–10. https://doi.org/10.1016/j.iccn.2018.05.007.

Alfheim, H.B., Rosseland, L.A., Hofsø, K., Småstuen, M.C., Rustøen, T., 2018. Multiple symptoms in family caregivers of intensive care unit patients. J. Pain Symptom Manage. 55 (2), 387–394. https://doi.org/10.1016/j.jpainsymman.2017.08.018.

Au, S. S., Roze des Ordons, A. L., Amir Ali, A., Soo, A., & Stelfox, H. T. 2019. Communication with patients' families in the intensive care unit: A point prevalence study. J. Crit. Care, 54, 235-238. doi:10.1016/j.jcrc.2019.08.031.

Baker, S.E., Edwards, R., 2012. How many qualitative interviews are enough? Expert voices and early career reflections on sampling and cases in qualitative research *National Centre for Research Methods Review Paper*. National Centre for Research Methods, Southampton.

Barbour, R.S., 2014. Analysing focus groups. In: Flick, U. (Ed.), The sage handbook of qualitative data analysis. Sage, London, pp. 313–326.

Bell, J.M., 2009. Family systems nursing: Re-examined. J. Fam. Nurs. 15 (2), 123–129. https://doi.org/10.1177/1074840709335533.

Benzein, E., Olin, C., Persson, C., 2015. 'You put it all together' – families' evaluation of participating in family health conversations. Scand. J. Caring Sci. 29 (1), 136–144. https://doi.org/10.1111/scs.12141.

Blom, H., Gustavsson, C., Sundler, A.J., 2013. Participation and support in intensive care as experienced by close relatives of patients–a phenomenological study. Intensive Crit. Care Nurs. 29 (1), 1–8. https://doi.org/10.1016/j.iccn.2012.04.002.

Bryant-Lukosius, D., Spichiger, E., Martin, J., Stoll, H., Kellerhals, S.D., Fliedner, M., De Geest, S., 2016. Framework for evaluating the impact of advanced practice nursing roles. J. Nurs. Scholarsh. 48 (2), 201–209. https://doi.org/10.1111/jnu.12199.

Buckley, P., Andrews, T., 2011. Intensive care nurses' knowledge of critical care family needs. Intensive Crit. Care Nurs. 27 (5), 263–272. https://doi.org/10.1016/j.iccn.2011.07.001.

Carlson, E.B., Spain, D.A., Muhtadie, L., McDade-Montez, L., Macia, K.S., 2015. Care and caring in the intensive care unit: Family members' distress and perceptions about staff skills, communication, and emotional support. J. Crit. Care 30 (3), 557–561. https://doi.org/10.1016/j.jcrc.2015.01.012.

Chaboyer, W., Thalib, L., Alcorn, K., Foster, M., 2007. The effect of an icu liaison nurse on patients and family's anxiety prior to transfer to the ward: An intervention study. Intensive Crit. Care Nurs. 23 (6), 362–369. https://doi.org/10.1016/j.iccn.2007.04.005.

Chesla, C.A., 2010. Do family interventions improve health? J. Fam. Nurs. 16 (4), 355–377. https://doi.org/10.1177/1074840710383145.

Craig, P., Dieppe, P., McIntyre, S., Michie, S., Nazareth, I., Petticrew, M., 2008. Developing and evaluating complex interventions: The new medical research council guidance. Br. Med. J. 337,. https://doi.org/10.1136/bmj.a1655 a1655.

Creswell, J.W., 2013. Qualitative inquiry and research design: Choosing among five approaches. Sage, Thousand Oaks.

Curry, L.A., Nembhard, I.M., Bradley, E.H., 2009. Qualitative and mixed methods provide unique contributions to outcomes research. Circulation 119 (10), 1442–1452. https://doi.org/10.1161/circulationaha.107.742775.

Curtis, J.R., Treece, P.D., Nielsen, E.L., Gold, J., Ciechanowski, P.S., Shannon, S.E., Engelberg, R.A., 2016. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. Am. J. Respir. Crit. Care Med. 193 (2), 154–162. https://doi.org/10.1164/rccm.201505-0900OC.

Cypress, B.S., 2011. The lived icu experience of nurses, patients and family members: A phenomenological study with merleau-pontian perspective. Intensive Crit. Care Nurs. 27 (5), 273–280. https://doi.org/10.1016/j.iccn.2011.08.001.

Daly, B.J., Douglas, S.L., O'Toole, E., Gordon, N.H., Hejal, R., Peerless, J., Lilly, C., 2010. Effectiveness trial of an intensive communication structure for families of long-stay icu patients. Chest 138 (6), 1340–1348. https://doi.org/10.1378/chest.10-0292.

Davidson, J.E., Aslakson, R.A., Long, A.C., Puntillo, K.A., Kross, E.K., Hart, J., Curtis, J.R., 2017. Guidelines for family-centered care in the neonatal, pediatric, and adult icu. Crit. Care Med. 45 (1), 103–128. https://doi.org/10.1097/ccm.0000000000002169.

Davidson, J.E., Jones, C., Bienvenu, O.J., 2012. Family responses to critical illness: Postintensive care syndrom - family. Crit. Care Med. 40 (2), 618–624.

Davidson, J.E., Strathdee, S.A., 2019. The future of family-centred care in intensive care. Intensive Crit. Care Nurs. 50, 3–4. https://doi.org/10.1016/j.iccn.2018.03.003.

Doane, G.H., Varcoe, C., 2005. Family nursing as relational inquiry: Developing health-promoting practice. Lippincott Williams & Wilkins, Philadelphia.

Eggenberger, S.K., Nelms, T.P., 2007. Being family: The family experience when an adult member is hospitalized with a critical illness. J. Clin. Nurs. 16 (9), 1618–1628. https://doi.org/10.1111/j.1365-2702.2007.01659.x.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., Kyngäs, H., 2014. Qualitative content analysis: A focus on trustworthiness. SAGE Open 4 (1), 1–10. https://doi.org/10.1177/2158244014522633.

Elo, S., Kyngäs, H., 2008. The qualitative content analysis process. J Adv Nurs 62 (1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x.

Erlingsson, C., Brysiewicz, P., 2017. A hands-on guide to doing content analysis. Afr. J. Emerg. Med. 7 (3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001.

Frivold, G., Dale, B., Slettebø, Å., 2015. Family members' experiences of being cared for by nurses and physicians in norwegian intensive care units: A phenomenological hermeneutical study. Intensive Crit. Care Nurs. 31 (4), 232–240. https://doi.org/10.1016/j.iccn.2015.01.006.

Frivold, G., Slettebø, Å., Dale, B., 2016. Family members' lived experiences of everyday life after intensive care treatment of a loved one: A phenomenological hermeneutical study. J. Clin. Nurs. 25 (3/4), 392–402. https://doi.org/10.1111/jocn.13059.

Gerritsen, R.T., Hartog, C.S., Curtis, J.R., 2017. New developments in the provision of family-centered care in the intensive care unit. Intens. Care Med. 43 (4), 550–553. https://doi.org/10.1007/s00134-017-4684-5.

Goldfarb, M.J., Bibas, L., Bartlett, V., Jones, H., Khan, N., 2017. Outcomes of patient- and family-centered care interventions in the icu: A systematic review and meta-analysis. Crit. Care Med. 45 (10), 1751–1761. https://doi.org/10.1097/ccm.0000000000002624.

Gottlieb, L.N., 2012. Strengths-based nursing care: Health and healing for person and family. Springer Publishing Company.

Graneheim, U.H., Lindgren, B.M., Lundman, B., 2017. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Educ. Today 56, 29–34. https://doi.org/10.1016/j.nedt.2017.06.002.

Graneheim, U.H., Lundman, B., 2004. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Educ. Today 24 (2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001.

Guest, G., Namey, E., McKenna, K., 2017. How many focus groups are enough? Building an evidence base for nonprobability sample sizes. Field Methods 29 (1), 3–22. https://doi.org/10.1177/1525822x16639015.

Haines, K.J., Denehy, L., Skinner, E.H., Warrillow, S., Berney, S., 2015. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. Crit. Care Med. 43 (5), 1112–1120. https://doi.org/10.1097/ccm.0000000000000865.

Hamilton, R., Kleinpell, R., Lipman, J., Davidson, J.E., 2020. International facilitators and barriers to family engagement in the icu: Results of a qualitative analysis. J. Crit. Care 58, 72–77. https://doi.org/10.1016/j.jcrc.2020.04.011.

Hamric, A. B., Hanson, C., Tracy, M. F., & O'Grady, E. 2014. Advanced practice nursing : An integrative approach. St. Louis, missouri: Elsevier/Saunders.

Hartmann, M., Bazner, E., Wild, B., Eisler, I., Herzog, W., 2010. Effects of interventions involving the family in treatment of adult patients with chronic diseases: A meta-analysis. Psychother. Psychosom. 79 (3), 136–148.

Hetland, B., Hickman, R., McAndrew, N., Daly, B., 2017. Factors influencing active family engagement in care among critical care nurses. AACN Adv. Crit. Care 28 (2), 160–170. https://doi.org/10.4037/aacnacc2017118.

Hetland, B., McAndrew, N., Perazzo, J., Hickman, R., 2018. A qualitative study of factors that influence active family involvement with patient care in the icu: Survey of critical care nurses. Intensive Crit. Care Nurs. 44, 67–75. https://doi.org/10.1016/j.iccn.2017.08.008.

Hwang, D.Y., Yagoda, D., Perrey, H.M., Tehan, T.M., Guanci, M., Ananian, L., Rosand, J., 2014. Assessment of satisfaction with care among family members of survivors in a neuroscience intensive care unit. J. Neurosci. Nurs. 46 (2), 106–116. https://doi.org/10.1097/JNN.0000000000000038.

International Family Nursing Association. (2017). Position statement on advanced competencies for family nursing Retrieved from https://internationalfamily-nursing.org/2017/05/19/advanced-practice-competencies/

Jayasekara, R.S., 2012. Focus groups in nursing research: Methodological perspectives. Nurs. Outlook 60 (6), 411–416. https://doi.org/10.1016/j.outlook.2012.02.001.
Kean, S., Mitchell, M., 2014. How do intensive care nurses perceive families in intensive care? Insights from the united kingdom and australia. J. Clin. Nurs. 23 (5–6), 663–672. https://doi.org/10.1111/jocn.12195.
Khalaila, R., 2013. Patients' family satisfaction with needs met at the medical intensive care unit. J. Adv. Nurs. 69 (5), 1172–1182. https://doi.org/10.1111/j.1365-2648.2012.06109.x.
Kisorio, L.C., Langley, G.C., 2016. End-of-life care in intensive care unit: Family experiences. Intensive Crit. Care Nurs. 35, 57–65.
Kleinpell, R., Heyland, D.K., Lipman, J., Sprung, C.L., Levy, M., Mer, M., Curtis, J.R., 2018. Patient and family engagement in the icu: Report from the task force of the world federation of societies of intensive and critical care medicine. J. Crit. Care 48, 251–256. https://doi.org/10.1016/j.jcrc.2018.09.006.
Kleinpell, Ruth, Zimmerman, Jerry, Vermoch, Kathleen L., Harmon, Lori A., Vondracek, Hugh, Hamilton, Rebekah, Hanson, Bruce, Hwang, David Y., 2019. Promoting Family Engagement in the ICU: Experience From a National Collaborative of 63 ICUs*. Crit. Care Med. 47 (12), 1692–1698. https://doi.org/10.1097/CCM.0000000000004009.
Kodali, S., Stametz, R.A., Bengier, A.C., Clarke, D.N., Layon, A.J., Darer, J.D., 2014. Family experience with intensive care unit care: Association of self-reported family conferences and family satisfaction. J. Crit. Care 29 (4), 641–644. https://doi.org/10.1016/j.jcrc.2014.03.012.
Kydonaki, K., Kean, S., Tocher, J., 2019. Family involvement in intensive care: A qualitative exploration of critically ill patients, their families and critical care nurses (input study). J. Clin. Nurs. https://doi.org/10.1111/jocn.15175.
Linnarsson, J.R., Bubini, J., Perseius, K.I., 2010. A meta-synthesis of qualitative research into needs and experiences of significant others to critically ill or injured patients. J. Clin. Nurs. 19 (21–22), 3102–3111. https://doi.org/10.1111/j.1365-2702.2010.03244.x.
Minton, C., Batten, L., Huntington, A., 2019. A multicase study of prolonged critical illness in the intensive care unit: Families' experiences. Intensive Crit. Care Nurs. 50, 21–27. https://doi.org/10.1016/j.iccn.2018.08.010.
Mitchell, M.L., Coyer, F., Kean, S., Stone, R., Murfield, J., Dwan, T., 2016. Patient, family-centred care interventions within the adult icu setting: An integrative review. Australian Critical Care 29 (4), 179–193. https://doi.org/10.1016/j.aucc.2016.08.002.
Moore, C.D., Bernardini, G.L., Hinerman, R., Sigond, K., Dowling, J., Wang, D.B., Shelton, W., 2012. The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. Crit. Care Nurs. Q 35 (4), 378–387. https://doi.org/10.1097/CNQ.0b013e318268fde3.
Moore, G.F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Baird, J., 2015. Process evaluation of complex interventions: Medical research council guidance. BMJ 350,. https://doi.org/10.1136/bmj.h1258 h1258.
Morgan-Trimmer, S., Wood, F., 2016. Ethnographic methods for process evaluations of complex health behaviour interventions. Trials 17 (1), 1–11. https://doi.org/10.1186/s13063-016-1340-2.
Morgan, D. L. 1997 / 2013. Planning and research design for focus groups Focus groups as qualitative research (Second Edition ed.). Thousand Oaks, California.
Nagl-Cupal, M., Hager, I., Mitterer, M., Mayer, H., Köck, S., 2012. Needs and need met of family members in the intensive care unit - a multicenter study. Pflegewissenschaft 14 (4), 206–216.
Nelson, J.E., Puntillo, K.A., Pronovost, P.J., Walker, A.S., McAdam, J.L., Ilaoa, D., Penrod, J., 2010. In their own words: Patients and families define high-quality palliative care in the intensive care unit. Crit. Care Med. 38 (3), 808–818.
Noome, M., Dijkstra, B.M., van Leeuwen, E., Vloet, L.C.M., 2016. Exploring family experiences of nursing aspects of end-of-life care in the icu: A qualitative study. Intensive Crit. Care Nurs. 33, 56–64.
O'Cathain, A., Thomas, K.J., Drabble, S.J., Rudolph, A., Hewison, J., 2013. What can qualitative research do for randomised controlled trials? A systematic mapping review. 3, (6). https://doi.org/10.1136/bmjopen-2013-002889 %J BMJ Open e002889.
Olding, M., McMillan, S.E., Reeves, S., Schmitt, M.H., Puntillo, K., Kitto, S., 2016. Patient and family involvement in adult critical and intensive care settings: A scoping review. Health Expect 19 (6), 1183–1202. https://doi.org/10.1111/hex.12402.
Onwuegbuzie, A.J., Dickinson, W.B., Leech, N.L., Zoran, A.G., 2009. A qualitative framework for collecting and analyzing data in focus group research. Int. J. Qual. Methods 8 (3), 1–21. https://doi.org/10.1177/160940690900800301.
Östlund, U., Persson, C., 2014. Examining family responses to family systems nursing interventions: An integrative review. J. Fam. Nurs. 20 (3), 259–286. https://doi.org/10.1177/1074840714542962.
Patton, M. Q. 2014. Qualitative research and evaluation methods: Integrating theory and practce (4th ed.). Thousand Oaks. CA: Sage.
Rusinova, K., Kukal, J., Simek, J., Cerny, V., 2014. Limited family members/staff communication in intensive care units in the czech and slovak republics considerably increases anxiety in patients' relatives–the depress study. BMC Psychiatry 14, 21. https://doi.org/10.1186/1471-244x-14-21.
Scheunemann, L.P., McDevitt, M., Carson, S.S., Hanson, L.C., 2011. Randomized, controlled trials of interventions to improve communication in intensive care: A systematic review. Chest 139 (3), 543–554. https://doi.org/10.1378/chest.10-0595.
Seaman, J.B., Arnold, R.M., Buddadhumaruk, P., Shields, A.-M., Gustafson, R.M., Felman, K., White, D.B., 2018. Protocol and fidelity monitoring plan for four supports. A multicenter trial of an intervention to support surrogate decision makers in intensive care units. Ann. Am. Thoracic Soc. 15 (9), 1083–1091. https://doi.org/10.1513/AnnalsATS.201803-157SD.
Shariff, A., Olson, J., Santos Salas, A., Cranley, L., 2017. Nurses' experiences of providing care to bereaved families who experience unexpected death in intensive care units: A narrative overview. Canad. J. Crit. Care Nurs. 28 (1), 21–29.
Shelton, W., Moore, C.D., Socaris, S., Gao, J., Dowling, J., 2010. The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit. Crit. Care Med. 38 (5), 1315–1320. https://doi.org/10.1097/CCM.0b013e3181d9d9fe.
Stayt, L.C., 2007. Nurses' experiences of caring for families with relatives in intensive care units. J. Adv. Nurs. 57 (6), 623–630. https://doi.org/10.1111/j.1365-2648.2006.04143.x.
Swiss Academy of Medical Sciences. (2015). Research with human subjects. Retrieved from https://www.samw.ch/en/Ethics/Topics-A-to-Z/Research-ethics.html
Thirsk, L.M., Moules, N.J., 2013. "I can just be me": Advanced practice nursing with families experiencing grief. J. Fam. Nurs. 19 (1), 74–98. https://doi.org/10.1177/1074840712471445.
Torke, A.M., Wocial, L.D., Johns, S.A., Sachs, G.A., Callahan, C.M., Bosslet, G.T., Burke, E.S., 2016. The family navigator: A pilot intervention to support intensive care unit family surrogates. Am. J. Crit. Care 25 (6), 498–507. https://doi.org/10.4037/ajcc2016730.
Turner-Cobb, J.M., Smith, P.C., Ramchandani, P., Begen, F.M., Padkin, A., 2016. The acute psychobiological impact of the intensive care experience on relatives. Psychol. Health Med. 21 (1), 20–26. https://doi.org/10.1080/13548506.2014.997763.
Vaismoradi, M., Turunen, H., Bondas, T., 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nursing & Health Sciences 15, 398–405. https://doi.org/10.1111/nhs.12048.
Vandall-Walker, V., Clark, A.M., 2011. It starts with access!: A grounded theory of family members working to get through critical illness. J. Fam. Nurs. 17 (2), 148–181. https://doi.org/10.1177/1074840711406728.
White, D.B., Angus, D.C., Shields, A.M., Buddadhumaruk, P., Pidro, C., Paner, C., Arnold, R.M., 2018. A randomized trial of a family-support intervention in intensive care units. N Engl J Med 378 (25), 2365–2375. https://doi.org/10.1056/NEJMoa1802637.
White, D.B., Cua, S.M., Walk, R., Pollice, L., Weissfeld, L., Hong, S., Arnold, R.M., 2012. Nurse-led intervention to improve surrogate decision making for patients with advanced critical illness. Am. J. Crit. Care: Off. Publicat. Am. Associat. Crit.-Care Nurses 21 (6), 396–409. https://doi.org/10.4037/ajcc2012223.
Wiegand, D.L., 2012. Family management after the sudden death of a family member. J. Fam. Nurs. 18 (1), 146–163. https://doi.org/10.1177/1074840711428451.
Wong, P., Liamputtong, P., Koch, S., Rawson, H., 2015. Families' experiences of their interactions with staff in an australian intensive care unit (icu): A qualitative study. Intensive Crit. Care Nurs. 31 (1), 51–63. https://doi.org/10.1016/j.iccn.2014.06.005.
Wright, L.M., Bell, J.M., 2009. Beliefs and illness: A model for healing. 4th Floor Press, Calgary, Alberta.
Wright, L.M., Leahey, M., 2013. Nurses and families: A guide to family assessment and intervention. F.A. Davies, Philadelphia, PA.